

Government of Alberta ■

Children and Youth Services

**REVIEW OF THE
FAMILY SUPPORT FOR
CHILDREN WITH DISABILITIES
MULTI-DISCIPLINARY TEAM (MDT) PROCESS**

**REPORT
AND
RECOMMENDATIONS**

SEPTEMBER 8, 2009

Table of Contents

Executive Summary iii

Introduction 1

The Review Process 2

What We Heard – A Synthesis of Inputs..... 3

WHAT'S WORKING..... 3

SURVEY RESULTS 4

OPPORTUNITIES FOR IMPROVEMENT 6

MDT Working Group Recommendations..... 8

Feedback Regarding Service Provider Capacity – Out of Scope..... 14

Closing Comments 15

Executive Summary

In keeping with Alberta Children and Youth Services' (ACYS') commitment to improvement, the department initiated a formal review of the Family Support for Children with Disabilities (FSCD) Program's Multi-Disciplinary Team (MDT) process in December 2008. The review was intended to assess the experiences of parents and other stakeholders with the MDT process, to identify what is working well, and to identify opportunities for improvement.

METHODOLOGY

Key components of the review process included:

- Establishment of an MDT Review Advisory Committee. It primarily included parents, together with representatives of disability organizations and clinicians. The Committee provided input on the review process itself, reviewed input from the stakeholder consultation, and provided their comments and perspectives on proposed recommendations.
- Focus groups with parents, service providers, clinicians and FSCD staff.
- Telephone interviews with parents, service providers, clinicians and physicians.
- A survey of parents who participated in at least one MDT within the last two years.
- Input of other recent MDT-related consultations, including:
 - Southern Alberta MDT Stakeholder Workshops, Fall 2008
 - FSCD Meeting with Professional Colleges, November 2008
 - Meetings with Provincial Stakeholder Advisory Committee members

WHAT WE HEARD

The parent survey indicated overall parent satisfaction with the MDT process:

- Most families (91%) said that they understand the purpose of the MDT and 85% said that they understand how MDT recommendations are used.
- A majority of families (84%) said they agreed with the recommendations for services that were made by the MDT panel.
- Overall, 94% of families said that they are given the opportunity and 85% said that their child's service providers are given the opportunity to actively take part in the MDT process.
- Three quarters of families (72%) indicated that they get the support they need from FSCD during the MDT process.
- Two-thirds of respondents (66%) agreed that "the FSCD Program clearly explains the reasons for its decisions" and three-quarters (75%) feel that the MDT recommendations are clearly explained to them.
- Families who have participated in the MDT process multiple times and those who have children 10 years of age and older expressed lower levels of agreement with the statements identified in the survey and were more likely to indicate a stronger disagreement.

Components or elements of the MDT process which were most frequently identified as working well (based on all sources of feedback) included:

- Funding based on individual needs
- Parent engagement in the MDT process
- Involvement of the child's service provider/clinicians
- The opportunity for peer review
- Multi-disciplinary collaboration
- Specific supports such as meetings with FSCD workers prior to MDT meetings and the ability of families to access video-conferencing to participate in MDT meetings

Parents who expressed overall satisfaction with the MDT process did identify some opportunities for improvement. The issues they raised were consistent with those raised by other parents who expressed lower levels of satisfaction with the MDT process. The areas identified for improvement can be consolidated under the general categories of:

- Decision-making and panel function
- Lack of equity and consistency
- Service provision and service capacity
- Family supports
- Information and communications
- Attitudes and expectations

WORKING GROUP RECOMMENDATIONS

Recommendation #1 – Clarify the FSCD Program's decision-making process regarding access to the MDT and ensure that parents receive sufficient rationale regarding the MDT recommendations.

Suggestions for improvement:

- Clarify the decision-making steps and the criteria for decisions requiring an MDT review through policy, training and information-sharing.
- Highlight the need to ensure that parents are provided with rationale for MDT recommendations through forms, training and clarified processes.

Recommendation #2 – Clarify the purpose of the MDT process and role of MDT panel members.

Suggestions for improvement:

- Clarify the intent of the MDT process and how MDT recommendations are used by the Director in making decisions about the provision of Specialized Services through policy, training and information-sharing with parents and other stakeholders.
- Clarify the consultative role of MDT panel members and the necessary expertise and qualifications of MDT members by defining their role and selection criteria.

- Clarify the roles of participants in the MDT process including parents, their service providers as well as advocates/support people and implement changes that promote opportunities for information-sharing and further understanding of the family's needs through policy, processes and training.
- Identify opportunities for parents and service providers to provide feedback regarding MDT recommendations.

Recommendation #3 – *Ensure that service providers play an integral role in the MDT process and service planning for children.*

Suggestions for improvement:

- Highlight the integral role that service providers play in the MDT process and promote collaborative service planning involving the parents, service providers and FSCD staff through policy and practice.
- Support service provider participation in the MDT by clarifying what documentation, progress reports or assessment information are required for the MDT; develop tools and checklists for service providers regarding MDT preparation; and determine the key elements and timelines for submitting service plans.

Recommendation #4 – *Ensure a timely and consistent MDT process regardless of where a family lives.*

Suggestions for improvement:

- Promote consistency by aligning the northern and southern MDT processes and clarifying the process requirements through policy and training.
- Clarify that, while local resources and service provision may look different, families do not require an additional MDT if they move to another region.
- Improve the timeliness of access to the MDT by: clarifying when an MDT is required; clarifying information and documentation requirements; supporting preparation for the MDT; using videoconference technology to support access and participation in MDT for rural families; sharing access to the necessary expertise for the MDT through regional collaboration; and offering a choice of on-paper or in-person MDT to families who meet a defined criteria.

Recommendation #5 – *Support parents in preparing for and participating in the MDT process.*

Suggestions for improvement:

- Clarify the role of the FSCD worker in supporting parents in preparing for the MDT (e.g., providing information about what information is needed, what things they might want to tell the MDT about, what kind of questions the MDT panel members might ask, how to best present their information).
- Develop information tools and checklists to assist families in preparing for the MDT.
- Provide training and tools for staff to promote cultural awareness and assessing where additional support may be required to mitigate barriers (e.g., support people or advocates, interpreter services, referral to multi-cultural supports or other community programs such as Parent Link Centres).

- Work together with families, service providers who are part of their team and other programs and services to support greater integration and coordination of services (e.g., explore FSCD's role and opportunities to work with Education to support a wrap-around approach for children with special needs, align and coordinate services for pre-school aged children).
- Support Human Resources with the FSCD Workload Assessment to consider the impact of caseload on support provided to parents.

Recommendation #6 – *Improve information-sharing and communication with parents, service providers and FSCD staff.*

Suggestions for improvement:

- Highlight the importance of and enhance information-sharing opportunities through: referral to advocacy organizations and parent support groups; enhancing the FSCD website; developing various print materials, information packages for new families, checklists and brochures specific to Specialized Services and the MDT process; utilizing technology such as videoconferencing, on-line video or webcasts; participating in community activities to capitalize on opportunities for information-sharing; utilizing the Child Disability Resource Link and promoting the Provincial Parent Advisory Committee as a mechanism for information-sharing between parents, Regional Parent Advisory Committees and the FSCD Program.
- Provide information to parents about what they should expect from their service provider, how to address issues or concerns with service providers (private hires or those contracted by FSCD) and assist parents in connecting with local service providers to access Specialized Services.
- Ensure that parents are advised of their options for concerns resolution and who to talk to if they have a concern or disagree with a program decision, through written communication materials, the website, as well as through policy and training.

Recommendation #7 – *Ensure consistent and transparent decision-making, clarify eligibility criteria and provide additional explanation for decisions about the provision of Specialized Services.*

Suggestions for improvement:

- Promote consistent interpretation and decision-making through regulation and policy while recognizing the need for individualized services and consideration for local resources.
- Clarify the intent and eligibility criteria for Specialized Services through regulation, policy, training and information-sharing with parents and other stakeholders, making it clear that Specialized Services are not limited to children with autism.
- Clarify that the Director makes decisions about administrative costs such as travel time, which are separate from the direct services recommended by the MDT or agreed upon with the family.
- Support flexibility in the use of agreed upon Specialized Services based on individual needs and service coordination that supports intended outcomes (e.g., reasonable flexibility is required in situations when a service provider was not available due to illness or vacation, where a more or less intensive involvement is necessary at different points in time through the course of the service plan, etc.)

- Identify the need to facilitate a transition period when moving from Specialized Services to other types and levels of service through policy and training.
 - Review the continuum of FSCD supports and services identified in the Regulation to consider the nature and level of other FSCD services that families may access when Specialized Services are no longer required.
 - Acknowledge through policy and training, the importance of good communication with parents, including the opportunity for discussion and providing explanations for program decisions.
-

Report and Recommendations

Introduction

Alberta Children and Youth Services (ACYS) assists children with disabilities and their families through the Family Support for Children with Disabilities (FSCD) Program. This program offers a range of supports and services, including Specialized Services for children with severe disabilities. The program uses a multi-disciplinary team (MDT) process to inform decisions around the provision of Specialized Services.

In keeping with the ongoing commitment to improvement, ACYS initiated a formal review of the MDT process in December 2008. The review was intended to identify what is working well with the existing MDT process, what is not working well and to make recommendations for improvements.

A Working Group made up of several department and Child & Family Services Authority (CFSA) managers, as well as a Communications representative, was responsible for implementing the review and developing recommendations based on stakeholder input. The formal review was intended to build upon efforts previously underway to identify opportunities to improve the MDT process, including consultation with families and other stakeholders in southern Alberta, a meeting with professional colleges, and discussions with stakeholder advisory committees.

Additional consultation with parents and other stakeholders from across the province was undertaken to seek input from a broader range of stakeholders, with parents being the primary audience. Feedback was invited through a survey of all parents who have been to an MDT within the past two years, as well as twelve focus groups held across the province and a number of one-on-one telephone interviews. ACYS also established an Advisory Committee to support the formal review process. The Advisory Committee was primarily made up of parents, together with representatives from disability organizations and clinicians. This committee provided advice on the development of the review process, reviewed and added their voices to the consultation feedback as well as provided their input to the development of the report and recommendations. The Committee reviewed, provided input and expressed their satisfaction with the draft report and recommendations in June 2009 before the committee disbanded. Committee members had a further opportunity for input on the revised report and recommendations in July 2009 before it was sent to executive management for approval.

This Report

A wealth of input and recommendations has been gathered through this review, and initial feedback from the Advisory Committee on how it was conducted has been positive. The MDT Working Group distilled a broad range of feedback from parents, service providers, clinicians, advocates and FSCD staff in order to develop recommendations. Although this review is

about the MDT process, the *experiences* of families seeking Special Services for their children with severe disabilities figure prominently in the feedback, and in the recommendations. The findings of the consultation covered a range of issues - from broad policy questions to detailed process improvements. Based on the feedback received, family's overall experience with the MDT process is positive. Yet, whether a family's experience was positive or negative, families expressed very similar issues and provided consistent recommendations for improvement. The feedback was passionate, especially for those families who feel their situation is not well understood, or that the process has not responded effectively to their individual needs.

The Review Process

The review included qualitative and quantitative methods, to enable both depth and breadth in data collection. The qualitative components (focus groups, telephone interviews, workshops, and meetings) offered an opportunity to hear stakeholder perspectives in detail and gather contextual information. The quantitative component (parent survey) made it possible to gauge the relative strength of opinions and the degree of commonality of issues and input.

A self-completion survey was mailed to all 650 families who participated in the MDT process at least once over the past two years. Respondents were given the option of submitting the survey by mail or online. A total of 141 completed surveys were received by the deadline, representing a response rate of 22%. The survey was developed, collated and analyzed by an independent consultant.

Twelve focus groups were conducted throughout the province, including eight focus groups with parents, two with service providers, and two with FSCD staff. An additional 17 telephone interviews supplemented the focus group sample. All focus groups and interviews were conducted by an independent consultant and were based on a semi-structured interview guide. A total of 53 parents/family members participated in the focus group consultations. Half were parents of younger children (0-6 years), and half had older children (7-18 years). About two-thirds of participants (67%) had a child with autism spectrum disorder (ASD). Other diagnoses represented include developmental delays, cerebral palsy, chromosomal anomalies, brain condition or injury, and a mental health disorder.

FSCD had been meeting with stakeholders to gather feedback around the MDT process before the formal review began. Feedback received through these meetings has been integrated into the data analysis including input from:

- *Southern Alberta MDT Stakeholder Workshops, Fall 2008*
A report summarizes recommendations from consultations with 16 parents, 16 service providers, and 10 FSCD staff in Lethbridge and Medicine Hat.
- *FSCD Meeting with the Professional Colleges, November 17, 2008*
Attendants at this meeting included representatives from the Alberta Colleges of Occupational Therapists (ACOT), Alberta College of Speech-Language Pathologists and Audiologists (ACSLPA), College of Physical Therapists of Alberta (CPTA), and College of Alberta Psychologists (CAP), as well as the Acting Director of the FSCD Program and other FSCD managers and staff.

- *Two meetings with Provincial Stakeholder Advisory Committee members. (December 2, 2007 and July 2, 2008)*
On two occasions between December 2007 and July 2008, FSCD met with representatives from the Provincial Stakeholder Advisory Committee to gather feedback on the MDT process.

What We Heard – A Synthesis of Inputs

A very broad range of input has been summarized in terms of:

- What families told us they believe works with the existing MDT process, specifically those elements that benefit and support them (**What's Working**).
- Quantitative results of the parent survey that included both open-ended and close-ended questions about families' experiences (**Survey Results**).
- Those aspects of the MDT process which need to be improved. The full array of input has been summarized in this report under the broader key themes that emerged (**Opportunities for Improvement**).

Participants throughout all components of the review process were invited to provide their candid feedback on the MDT process as well as recommendations for improvement. Their recommendations were considered by the Working Group and are reflected in the seven key recommendations and suggestions for improvement presented within this report.

WHAT'S WORKING

Parents and other stakeholders highlighted a number of benefits and positive aspects of the MDT process and agreed that the following elements of the MDT process should be sustained or enhanced:

- **Funding based on individual needs** - Parents in every focus group expressed gratitude for the funding that is available in this province for Specialized Services. Many of them talked about the difference this funding has made in the lives of their children.
- **Parent engagement in the MDT process** - Participants from all stakeholder groups said that parent involvement was a critical part of the MDT process. Their presence in the MDT meeting helps to ensure that the child's plan gets framed around the learning priorities of the family. The MDT meeting also allows parents to ask questions of the MDT panel members.
- **Involvement of the child's service providers/clinicians** - The option of having the child's service providers/clinicians participate in the MDT meeting was identified by a number of parents as positive. Parents feel reassured by their presence because these clinicians have a working understanding of the child and can help parents articulate the rationale for the services they are requesting. Most parents wanted to see this aspect of MDT reinforced, with their service providers having greater input or involvement in the process.

- **Peer review** - The opportunity for peer review was identified as a very positive aspect of the existing MDT process by a number of parents, service providers, and FSCD staff. Some felt that it helped to increase accountability. Others welcomed the opportunity for case conferencing, saying that the MDT meeting gave parents and service providers a chance to hear ideas and suggestions from other professionals. Parents said that they saw value in having other professionals review the file, and would not want to lose that aspect of the process altogether (although they would like the child's clinicians/service providers to have an increased role in decision-making).
- **Multi-disciplinary collaboration** - Stakeholders said that, when it works well, the multi-disciplinary approach is a significant asset. Participants in the focus groups appreciated when FSCD workers attended MDT meetings, saying it helped them to feel supported and gave the worker a more accurate understanding of their child's needs. Service providers commented on the value of working with colleagues from other disciplines to provide an integrated approach to service provision.
- **Specific supports** - Some parents identified specific supports that were helpful, including the option to attend the MDT meeting via videoconference and meeting with their FSCD worker before the MDT to ensure all of the documentation is in place. Parents also said that being given a year to transition out of Specialized Services (rather than being cut off suddenly) was helpful.

SURVEY RESULTS

The survey data suggests that, overall, families' experience of the MDT process is positive, although some notable differences exist among families who have participated in the process more than once, and among families who have older children.

- The majority of families (84%) said they agreed with the recommendations for services that were made by the MDT panel. Agreement with this statement ranged from a high of 93% for first time families to 74% for families that have participated in the process four times or more; and 91% for families with children aged two to five years to 61% for families with children aged 10 years and older.
- Overall, 94% of families indicated that they are given an opportunity to actively take part in the MDT meeting. Agreement with this statement decreased for families who have participated in the MDT process more than three times (88%), and for families who have children 10 years of age and older (84%).
- Roughly three-quarters of families (72%) indicated that they get the support they need from FSCD during the MDT process. Of the 28% of families who disagreed with this statement, disagreement was highest among families with children 10 years of age and older (35% disagreed), and families who have participated in the process two to three times (34% disagreed).

- A majority of families (85%) said they understand how MDT recommendations will be used to make decisions for their children. 79% of families who have participated in MDT over three times agreed with this statement, however, more of these families indicated strong disagreement (17%) than other groups of families (5%). Similarly, while the majority of families with children 10 years of age or older agreed with the statement (74%), 21% strongly disagreed.
- Most families (91%) said they understand the purpose of the MDT, although families who had participated in MDT over three times and families with children 10 years of age or older, were more likely than other families to strongly disagree with this statement (13% and 11% respectively, compared to 5% of other families).
- Roughly three-quarters of respondents (77%) indicated they understand the information requirements for MDT. Disagreement with this statement (23%) was highest among families who have participated in the process only once and families with children two to five years of age.
- Eighty-five percent of families agreed that their child's service providers have an opportunity to actively take part in the MDT meeting. The level of agreement decreased to 78% for families who participated in the MDT process a number of times and 67% for those with children 10 years of age or older.
- Three-quarters of respondents (75%) indicated that they feel the MDT recommendations are clearly explained to them. The level of agreement decreased to 71% for families who participated in the MDT process a number of times and 69% for those with children 10 years of age or older.
- Two-thirds of respondents (66%) agreed with the statement "the FSCD Program clearly explains the reasons for its decisions." Agreement with this statement decreased among families who have participated in the MDT process more than once (58%).
- The majority of families who have participated in the MDT process only once (93%) and families with children two to five years of age (89%) agree that the MDT process recognizes/acknowledges the strengths of children and families. 65% to 74% of other families agreed with this statement.

Parents who expressed overall satisfaction with the MDT process also identified opportunities for improvement. Their suggestions were consistent with that of other parents and stakeholders and the issues emerging through the focus group data. While the *nature* of the issues is consistent, the *level* of concern varies significantly among stakeholders. For the most part, parents were positive about the MDT process and, while most parents expressed general satisfaction, there are some parents highly frustrated with the MDT process and deeply concerned about the consequences of the current process for themselves and other families.

OPPORTUNITIES FOR IMPROVEMENT

The issues and the recommendations identified by parents and other stakeholders have been grouped in six inter-related categories:

1. Decision-making and panel function

Decision-making emerged as a key area for improvement. A number of stakeholders feel that the criteria used to determine eligibility (for Specialized Services) and service levels are unclear. For this reason, the MDT process sometimes feels arbitrary and subjective.

Many also expressed concerns about the composition and function of the MDT panel. Despite FSCD communications about the consultative nature of the MDT, parents and service providers perceive the MDT panel to be a *de facto* decision-maker. Given this perception, stakeholders expressed concerns about the fact that the MDT panel members have no client relationship with the child.

Other related issues were:

- Rationale for MDT recommendations and FSCD decisions about Specialized Services are not always clearly explained
- In some cases, decisions about the provision of Specialized Services appear to be predetermined by FSCD even before the MDT meeting or recommendations
- Legislation is open to multiple interpretations, leading to contested decisions
- The level of documentation required for the MDT is time and resource intensive
- Newer therapies are not often recognized or funded as a Specialized Service (e.g., Relationship Development Intervention [RDI])

A number of the recommendations included suggestions to develop clear criteria, further involve service providers in the MDT process, and increase opportunities for the MDT panel members to better understand the individual needs and circumstances of each family.

2. Equity and consistency

One of the issues expressed most strongly throughout consultation was about access to the MDT. Stakeholders were particularly concerned about what they perceived to be inappropriate “gate-keeping” by the FSCD Program. Based on their interpretation of the legislation and purpose of the MDT process, they felt that the perceived “gate-keeping” was inappropriate for three reasons: FSCD program staff do not have the clinical training to support decisions about access to MDT; eligibility for Specialized Services is supposed to be determined by a multidisciplinary team; the process becomes vulnerable to the understanding, perceptions, and judgments of individual workers.

Contributing to a sense of inequity is the perception that processes, expectations, messaging, decisions, and requirements vary considerably within and between regions. For example, participants said there are inconsistencies in:

- The degree to which the FSCD Program helps to prepare parents
- The amount of time the FSCD worker spends with the family and their service team
- The degree to which FSCD workers advocate for the family

Stakeholder recommendations centre on addressing barriers to accessing the MDT, and developing and communicating provincial standards and procedures.

3. Service provision and capacity

Service provider capacity was identified as a significant problem in Alberta, especially in rural areas. Parents encounter long waiting lists and rural families are challenged to find service providers/clinicians who will travel outside of the major centres. They also face many challenges because of high turnover rates among clinicians and aides.

While issues such as the availability of service providers and service delivery are outside the scope of this review, quality and intensity of services directly impact a child's progress, and need to be considered in the program's decision-making. Parents repeatedly pointed out that three years of Specialized Services can often amount to considerably less as a result of time delays and gaps in services.

Other stakeholder concerns around service capacity and provision specific to the MDT process included:

- Wait times for MDT meetings result in delayed access to required services
- The degree to which a child's funding for Specialized Services goes towards administrative costs, assessments, and in the case of rural families, to travel.
- Parents do not feel there are any service options outside of Specialized Services. This creates an all-or-nothing dynamic where families feel compelled to fight for continued Specialized Services

Recommendations in this area centred on improving access to services, supporting families in dealing with service issues, creating service options outside of Specialized Services, and finding ways to ensure that allocated service hours do not get consumed by other administrative demands.

4. Family support

Families identified a number of support needs. While much of this related to informational support (discussed in the next section), other forms of support also identified as lacking included:

- Help in gathering documentation for the MDT
- Preparing for the MDT and navigating the MDT process
- Identifying appropriate service providers and getting services in place

Families said the MDT process is sometimes "slow and rigid" and difficult to navigate and wanted FSCD workers to be more empathetic in their approach.

In addition to recommendations to improve FSCD support to families, stakeholders identified ways that service providers could help families throughout the MDT process.

5. Information and communication

A number of stakeholders expressed significant frustration at what they perceive to be very limited information and communication from FSCD. Stakeholders identified a lack of clear, consistent information about the purpose of the MDT process and Specialized Services, options available through Specialized Services, and the options available if they do not agree with a decision (e.g., appeal). Other specific information concerns included:

- Communication about the services available in each community is limited
- Lack of change management: families and FSCD workers are not always informed of changes to the MDT process

A number of recommendations emerged around print and web-based information, checklists, and tools to help parents and service providers better understand the MDT process and the purpose of Specialized Services.

6. Attitudes and Expectations

Parents and service providers said that the attitudes of some FSCD staff contribute to an adversarial relationship. They said that FSCD sometimes makes them feel as if they are out to “milk the system,” when they are really just trying to optimize their child’s potential. Several suggested a link between this assumption and the lack of communication from FSCD about options available through Specialized Services.

A different theme emerged in consultations with service providers, physicians, and FSCD staff, some of whom worry that parents are being “set up for failure” because clinicians offer parents “too much hope.” These stakeholders are concerned that parents’ expectations of very significant advances are not supported by the evidence. They also expressed concerns around limitations in financial resources and provider capacity, saying that parental expectations need to be based on a realistic assessment of what services are available.

Stakeholders also talked about:

- the MDT process being intimidating and stressful for many parents who feel like they need “proof” to justify their child’s needs
- being afraid to talk about any gains that their child is making because the process seems to be focused on deficits

While a number of the issues that stakeholders identified were related to attitudes and expectations, few recommendations emerged in this area. Stakeholders’ suggestions centred on adjusting attitudes towards progress, and increasing FSCD’s trust in service providers. They also said implementing the recommendations from the consultation process would “go a long way” in building relationships.

MDT Working Group Recommendations

The high degree of consistency in the nature of the issues and in aspects of the MDT process that would benefit from improvements offers a solid foundation on which to build recommendations.

The Working Group considered the wealth of feedback provided by parents and other stakeholders and kept key insights of the Advisory Committee in mind in considering its recommendations. The Advisory Committee emphasized that the MDT process and decision-making about the provision of Specialized Services must ensure a balance between sufficient *flexibility* to address individual needs and *clear/consistent* policies and practices to provide equity for families.

While the purpose of the review was to consider the MDT process specifically, stakeholder consultation revealed that increased information-sharing about the FSCD Program and additional clarity related to the provision of Specialized Services would contribute to a more positive experience with the MDT process.

The following recommendations address the key issues heard most frequently during the stakeholder consultation. These recommendations are drawn directly from the consultation themes. They enable government action and position FSCD to address many of the specific operational recommendations made by parents and other stakeholders.

Recommendations 1 to 5 deal specifically with the MDT process and identify opportunities for improvement.

Recommendation #1 – Clarify the FSCD Program’s decision-making process regarding access to the MDT and ensure that parents receive sufficient rationale regarding MDT recommendations.

- 84% indicated that they agreed with the MDT recommendations they received.
- We heard from many stakeholders, however, that there is a lack of clarity and consistency about when an MDT is required, who decides if an MDT is needed and what steps parents can take if they disagree.
- 75% of families said that MDT recommendations were clearly explained to them. Stakeholders identified an opportunity to improve the rationale provided regarding MDT recommendations along with the opportunity for parents (and service providers as appropriate) to discuss the recommendations with the FSCD Program before decisions regarding Specialized Services are made.

Suggestions for improvement:

- Clarify the decision-making steps and the criteria for decisions requiring an MDT review through policy, training and information-sharing.
- Highlight the need to ensure that parents are provided with rationale for MDT recommendations through forms, training and clarified processes.

Recommendation #2 – Clarify the purpose of the MDT process and role of MDT panel members.

- The majority of families (91%) said that they understand the purpose of the MDT process.
- Multi-disciplinary collaboration and the opportunity for peer review were highlighted as positive aspects of the MDT process. Some felt that the MDT process also helps to increase accountability for parents, service providers and FSCD staff.
- Stakeholders asked for further clarification regarding the intent of the MDT process; selection and qualifications of MDT members; the role of the MDT members (i.e., consultation versus assessment or decision-making); how MDT recommendations are used by the Director in making decisions about the provision of Specialized Services and the timeframes for MDT recommendations (e.g., is another MDT required one year from the date of the last MDT or one year from when Specialized Services started).
- Parents, as well as other stakeholders, identified the need to ensure sufficient time to review and discuss the child's and family's needs. They also suggested developing a defined feedback mechanism to the MDT panel members regarding their recommendations.

Suggestions for improvement:

- Clarify the intent of the MDT process and how MDT recommendations are used by the Director in making decisions about the provision of Specialized Services through policy, training and information-sharing with parents and other stakeholders.
- Clarify the consultative role of MDT panel members and the necessary expertise and qualifications of MDT members by defining their role and selection criteria.
- Clarify the roles of participants in the MDT process including parents, their service providers and their advocates/support people, and implement changes that promote opportunities for information-sharing and further understanding of the family's needs through policy, processes and training.
- Identify opportunities for parents and service providers to provide feedback regarding MDT recommendations.

Recommendation #3 – Ensure that service providers play an integral role in the MDT process and service planning for children.

- Parents identify their service providers as a key source of information and regard service provider participation as a positive feature of the existing MDT process. Service provider participation was identified as something that is working and should be enhanced.
- While 77% of the parents who responded to the survey said that they understand the information requirements for the MDT process, stakeholders identified the need to clarify what information service providers need to prepare for the MDT, expectations around service plans and information about the MDT process to assist them in preparing for and supporting the family at the MDT.

Suggestions for improvement:

- Highlight the integral role that service providers play in the MDT process and promote collaborative service planning involving the parents, service providers and FSCD staff through policy and practice.
- Support service provider participation in the MDT by clarifying what documentation, progress reports or assessment information are required for the MDT; develop tools and checklists for service providers regarding MDT preparation; and determine the key elements and timelines for submitting service plans.

Recommendation #4 – *Ensure a timely and consistent MDT process regardless of where family lives.*

- Efforts to improve and streamline the MDT process over time may have resulted in families experiencing an inconsistent process if they have an older child who has received specialized services for a number of years and they have participated in two or more annual MDTs. These parents, as well as other stakeholders, highlighted a lack of consistency in the MDT process across regions and over time.
- Concerns were also identified about the timeliness of the MDT process and the frequency of MDTs.

Suggestions for improvement:

- Promote consistency by aligning the northern and southern MDT processes and clarifying the process requirements through policy and training.
- Clarify that, while local resources and service provision may look different, families do not require an additional MDT simply because they move to another region.
- Improve the timeliness of access to the MDT by: clarifying when an MDT is required; considering options for on-paper or in-person MDT meetings; clarifying information and documentation requirements and supporting preparation for the MDT; using videoconference technology to support access and participation in MDT for rural families; and sharing access to the necessary expertise for the MDT through regional collaboration.

Recommendation #5 – *Support parents in preparing for and participating in the MDT process.*

- Stakeholders identified parent participation in the MDT process as critical and beneficial in ensuring that family's priorities are reflected in their child's service plans. They highlighted parent participation as a positive aspect of the existing MDT process, suggesting that this be continued and enhanced.
- 72% of families said that they received the support they needed from the FSCD Program during the MDT process. Additional support to help families prepare for the MDT process so that they can more effectively participate and communicate their child's and family's needs was requested. Stakeholders identified that cultural differences, language barriers or other circumstances may present challenges for some families that should also be considered.

- Several stakeholders commented on the need for Health and Wellness, Education, and ACYS to work together in a more integrated way and some expressed frustration about the distinction between home and school services/funding, saying that it is artificial and does not support an integrated approach.

Suggestions for improvement:

- Clarify the role of the FSCD worker in supporting parents in preparing for the MDT (e.g., providing information about what information is needed, what things they might want to tell the MDT about, what kind of questions the MDT panel members might ask, how to best present their information).
- Develop information tools and checklists to assist families in preparing for the MDT.
- Provide training and tools for staff to promote cultural awareness and assessing where additional support may be required to mitigate barriers (e.g., support people or advocates, interpreter services, referral to multi-cultural supports or other community programs such as Parent Link Centres).
- Work together with families, service providers who are part of their team and other programs and services to support greater integration and coordination of services (e.g., explore FSCD's role and opportunities to work together with Education to support a wrap-around approach for children with special needs, align and coordinate services for preschool aged children).
- Support Human Resources with the FSCD Workload Assessment to consider the impact of caseload on support to parents.

Recommendation 6 is identified as key to improving families' understanding of the MDT process and supporting their preparation for the MDT, and is critical to supporting information-sharing regarding the FSCD Program overall. Because of the clear and consistent feedback regarding the need for improved communication and information beyond just the MDT process, this recommendation is highlighted as distinct from supporting parents with the MDT process.

Recommendation #6 – Improve information-sharing and communication with parents, service providers and FSCD staff.

- The need for improved communication and information-sharing was highlighted by parents. They suggested that information needs to be provided in multiple formats and made available at various times throughout a family's involvement with the FSCD Program.
- Parents are asking for information about the FSCD Program and the range of services available, in addition to information about other government programs and services, tax programs or benefits, community supports and resources, advocacy and parent support groups.

- More specific to the MDT process and Specialized Services, parents identified the need for a checklist of what documentation is required for the MDT, how to prepare for the MDT, what types of questions will be asked at MDT, information about how to access local service providers, what to look for in hiring a service provider, how to address issues or concerns with service providers and employer/employee responsibilities.
- The need to ensure that parents are advised of their options if they disagree with an FSCD Program decision continues to be an area for improved information-sharing, not only with respect to their formal concern resolution options but also who to talk to within the FSCD Program about their concerns.

Suggestions for improvement:

- Highlight the importance of and enhance information-sharing opportunities, through referral to advocacy organizations and parent support groups; enhancing the FSCD website; developing various print materials, information packages for new families, and checklists and brochures specific to Specialized Services and the MDT process; utilizing technology such as videoconferencing, online video or webcasts; participating in community activities to capitalize on opportunities for information-sharing; utilizing the Child Disability Resource Link and promoting the Provincial Parent Advisory Committee as a mechanism for information-sharing between parents, Regional Parent Advisory Committees and the FSCD Program.
- Provide information to parents about what they should expect from their service provider, how to address issues or concerns with service providers (private hires or those contracted by FSCD) and assist parents in connecting with local service providers to access Specialized Services.
- Ensure that parents are advised of their options for concerns resolution and who to talk to if they have a concern or disagree with a program decision, through written communication materials, the website, and through policy and training.

Recommendation 7 is not specific to the MDT process but responds to concerns raised regarding clarity and consistency in the provision of Specialized Services and how this impacts access to the MDT process and MDT recommendations.

Recommendation #7 – *Ensure consistent and transparent decision-making, clarify eligibility criteria and provide additional explanation for decisions about the provision of Specialized Services.*

- Parents and other stakeholders, including FSCD staff, are unclear about the intent and purpose of Specialized Services. There are varying interpretations of the Regulation, policies and eligibility criteria for Specialized Services among families, service providers and FSCD staff. While clear and consistent decision-making and criteria are being requested, stakeholders also want to ensure flexibility and responsiveness to individual needs.

- Families also feel that they are not provided with sufficient explanation for the decisions being made by the FSCD Program, leaving them with the perception that decisions are subjective and unpredictable. While 66% of families agreed with the statement that “the FSCD Program clearly explains the reasons for its decisions” there is opportunity for improvement.
- Parents identified that being given time to transition from Specialized Services to other levels of support was a positive aspect of the existing process; however, identified the need to make transitioning a consistent practice in all areas of the province and with all families.

Suggestions for improvement:

- Promote consistent interpretation and decision-making through regulation and policy while recognizing the need for individualized services and consideration for local resources.
- Clarify the intent and eligibility criteria for Specialized Services through regulation, policy, training and information-sharing with parents and other stakeholders, making it clear that Specialized Services are not limited to children with autism.
- Clarify that the Director makes decisions about the provision of specialized services including direct services as well as any additional administrative costs such as travel time for service providers.
- Support flexibility in the use of agreed upon Specialized Services based on individual needs and service coordination that supports intended outcomes (e.g., reasonable flexibility is required in situations when a service provider was not available due to illness or vacation, where a more or less intensive involvement is necessary at different points in time through the course of the service plan, etc.).
- Identify the need to facilitate a transition period when moving from Specialized Services to other types and levels of service through policy and training.
- Review the continuum of FSCD supports and services identified in the Regulation to consider the nature and level of other FSCD services that families may access when Specialized Services are no longer required.
- Acknowledge through policy and training, the importance of good communication with parents, including the opportunity for discussion and providing explanation regarding program decisions.

The Working Group believes that by taking action on these recommendations, families’ experience with the MDT process will improve significantly. In the words of one Advisory Committee member, “We must all stay focused on the *purpose* – and that’s to support families and their children.”

Feedback Regarding Service Provider Capacity – Out of Scope

This review focused specifically on the MDT process. However, stakeholders also raised issues beyond the scope of this review, many of which have a significant impact on the overall question of whether families are receiving the services they need.

Parents and other stakeholders who participated in the MDT review identified service provider capacity, both in terms of quality and availability, as barriers to accessing Specialized Services. High levels of staff turnover in agencies, agency staff skills and qualifications, rates of pay for providers and parents having to top-up service provider rates were noted as concerns.

Parents suggested that service providers need to be more innovative in how they provide services given the resource and economic realities and that service providers need to be accountable for the services they provide. For example, the idea of more group services and less one-on-one service was offered as a suggestion that would help maximize families' access to limited resources.

Some parents and stakeholders suggested the FSCD Program should establish standards and criteria about who can provide services and develop appropriate accountability measures. Stakeholders pointed out that quality aide support is as important to address and as critical of an issue to a child's progress as are issues related to the MDT process.

Closing Comments

The MDT Working Group would like to thank each member of the Advisory Committee for their diligence, hard work and candid feedback. The insights and experience they brought to the table provided significant value to the review process, and enabled better understanding of the issues and opportunities. This committee was instrumental in completing this review and supported the MDT Working Group in developing the recommendations. After five months, this committee disbanded at the end of June 2009 with Committee members expressing their satisfaction with the way the review was conducted and positive feedback on the draft report and recommendations.

The Working Group would also like to thank every parent, clinician, service provider, physician, advocate and FSCD staff member who took the time to participate. Your feedback was invaluable and input critical to this review. Parents in every focus group identified that services and funding based on individual need have made a difference in the lives of their children. We heard many times about the importance of balancing individual needs and the flexibility to address the uniqueness of families and their circumstances with the need for clear and consistent decision-making and processes. At the same time, stakeholders cautioned us to ensure any changes which might be made in response to this review do not result in excluding some families from the MDT process or from eligibility for Specialized Services. Balancing the need for clear, consistent and transparent decisions with flexibility and individualization will be a challenge in implementing the recommendations.

The wealth of feedback gathered has identified the positive aspects of the existing MDT process as well as shone a light on the challenges families experience with accessing Specialized Services and the MDT process. The Working Group believes that clarification of the intent and purpose of Specialized Services and the role of the MDT will promote enhanced accountability for the FSCD Program, parents and service providers in achieving the intended outcomes for children and families. We are also optimistic that improved clarification and consistency in the provision of Specialized Services and in the MDT process will foster greater trust with parents and service providers – a critical outcome for *all* stakeholders.